



## Brain Injury Awareness Day on Capitol Hill in Washington D.C

*Submitted by Board Member Alina Fong*

I attended Brain Injury Awareness Day on Capitol Hill in Washington, DC. The energy in the room was as impressive as the location. It was amazing to see so many individuals from different backgrounds coming together to bring awareness to an issue that affects so many Americans. Like us, others were there to show that they understand the impact a brain injury can have on an individual and that there are treatment options, resources, and supports available to them.

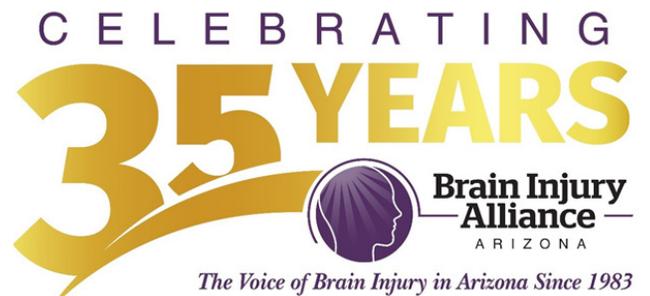
While attending, we spoke with various exhibitors there, many of whom were familiar faces. These included NICoE (National Intrepid Center Of Excellence). Their message is related to assisting military personnel past and present with traumatic brain injuries that are a result from the service to their country. Not only do they employ various therapeutic techniques, but they also advocate and utilize various imaging techniques, including fmri. Meeting representative Pascrell was another honor. Dr. Sugerman and I, with Dr. Sawicki, were able to meet with Mitt Romney's staff and implore him to join the Brain Injury Alliance of Utah as well as the TBI Task Force. Again, the experience was overall quite wonderful and rewarding.

We look forward to attending again next year!

## State Spotlight: The Brain Injury Alliance of Arizona

**All Systems a Go for the Unmasking Brain Injury Project!**

Unmasking Brain Injury will be at the Rays of Hope Conference in Phoenix on May 17th. Click here to register. Registration opens at 8:15AM and the conference runs from 9:00AM-3:30PM. Join us to see the entire exhibit, over 200 masks and counting. Thanks to a sponsorship from Chekela Turner's Place, survivors of brain injury and care-givers can make their own masks during the conference on May 17th. Ready, set, get inspired to share your story!



### Sponsorship Needed to Help the Exhibit Travel the State!

The reaction and impact has been incredible, but the display can't get from Bisbee to Flagstaff on its own. Sponsorships from \$500- \$5,000 are available. Your logo or family name will be on the display as it travels the state, getting maximum exposure at conferences and in public areas. Contact info@biaaz.org for more information about sponsorships. We also need sponsorships to fund mask making-parties!

There is still time to make your mask. Join us for an upcoming mask-making party. All supplies are provided! Just bring yourself.



- Phoenix – Saturday, April 20 from 3:00-5:00PM or Tuesday, April 23 from 1:00-3:00PM at the Brain Injury Alliance of Arizona office

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## The Role of Support Groups in Living Well after Brain Injury: A Behind the Scenes Look at Best Practices

Presented by Carrie Collins-Fadell

Register now for the USBIA May Webinar (instructions at the bottom of this message). May 1, 2019. (1:00pm CDT, 2:00pm EDT)

For many BIA chapters, support groups were one of the first and are the longest running programs. What role do they play in brain injury recovery and reconnection? What are some best practices that BIA chapters can implement to support these groups? How can chapters protect themselves in a litigious world? How can you survey your population to know where and when to implement new support groups? Join us as Carrie Collins-Fadell examines all these issues and more as the director of the Arizona Brain Injury Alliance leads a discussion on all things support groups. Carrie has presided over the expansion of existing support groups in Arizona to include a young adults concussion discussion group and a men's all ages support group with varied results. She has also picked up the pieces after members of a support group left to form their own nonprofit.

### About the speaker

Carrie Collins-Fadell is the Executive Director of the Arizona Brain Injury Alliance and a Board Member of the United States Brain Injury Alliance.

### How to register

To register, send an email to Monica Rodgers at [mrogers@usbia.org](mailto:mrogers@usbia.org). In the subject line place "Webinar Registration." Monica will send you an invitation with instructions on joining the webinar before the event.

- Scottsdale – Thursday, April 11 from 11:00AM-1:00PM Encompass Health Rehabilitation Hospital of Scottsdale
- Tucson – Friday, June 21 from 10am -12pm at TMC for Seniors

### Author Mimi Hayes Makes a Mask for the Brain Injury Alliance Unmasking project!

The author of, "I'll Be Okay, It's Just A Hole In My Head" jumped at the chance to contribute a mask to the Arizona Brain Injury Alliance project and designed a mask that tells her brain injury story, including nearly having a brain aneurism on a blind date. She unveiled her mask on LIVE TV in Phoenix! You can [watch Mimi](#)

[tell Holly Morgan at AZ Daily Mix all about her mask here.](#)

### Senators and Representatives Meet With Mask Artists At AZ Capitol

Just in time for March, Brain Injury Awareness Month, the masks made an appearance twice at the State Capitol and several mask artists joined us at events across the state to educate and inspire. You can [see the display at Phoenix City Hall for March, Brain Injury Awareness Month, here.](#)

For questions about any of the Brain Injury Alliance of Arizona activities and events, please contact them at 888-500-9165 or [outreach@biaaz.org](mailto:outreach@biaaz.org)!



## USBIA State News

### Brain Injury Alliance of Colorado



The Brain Injury Alliance of Colorado (BIAC) was awarded ACL funding in 2018 to research, develop, and implement a new Peer Mentorship Program. The program took to heart the vision statement of BIAC, “that all survivors of injury to the brain thrive in their community,” and began exploring what this means to survivors. Primary themes that arose were self-care, building confidence and believing in abilities, as well as life-purpose and meaning.

Peer support offers mentors the opportunity to be a role model and step into leadership by giving back to other brain injury survivors as someone who “has been there,” and giving peer mentees the opportunity to improve one’s life by being supported by someone that “really understands because they know what it is like to have a brain injury.”

BIAC is grateful for all those programs and associations that have had mentorship programs and took the time to share their experience and knowledge, which has informed our program. A special thank you is extended to the team of people from Mt. Sinai School of Medicine, the Brain Injury Association of New York, the Brain Injury Alliance of New Jersey, and the National Self-Help Clearinghouse, which developed and shared their mentorship program manuals, which have been incredibly assistive to program development!

During the process of researching models of peer mentorship, the mental health system stood out in terms of professionalism and experience, as they have developed their current model over many decades and are now

beginning to move into paid mentorship opportunities. The mental health mentorship programs identified the importance of language that supports self-efficacy, self-empowerment, and hope. Additionally, BIAC found the brain injury mentoring program Headstrong, with a biologist, Desirée Douglass at the lead utilizing neuroplasticity as a platform for integrating these features. BIAC discovered Dr. Jeffrey Kreutzer’s research on resilience and will be utilizing this focus to support brain injury survivors to explore different approaches that may allow improved outcomes functionally and socially (<http://www.tbinrc.com/>). BIAC’s Peer Mentorship Program will be encouraging participants to explore what wholeness is at this point in their life, from the perspective of the Wellness Wheel and to take steps to integrate this into their lives.

Our program has a few final touches and will be launching this spring. We have been inspired by the support of our local community and those supporting the development of our program. A few survivors have assisted with defining the “phases from brain injury to thriving,” so that participants have a basic road map. The spirit of our program launch is motivated by a quote from a survivor at a recent focus group. Laura Laureta shared, “We are not alone, we simply haven’t met one another yet.”

### Brain Injury Alliance of Connecticut



The Hartford Foundation for Public Giving invited 49 nonprofits to a series of workshops where we received valuable coaching in how to establish revenue generating ventures. Thirty-two nonprofits submitted applications for the next phase of the initiative, which consists of a 30-month business planning, implementation and tracking process,

and 10 were selected to move forward. The Brain Injury Alliance of Connecticut (BIACT) was selected as one of the ten participants. This is provided in partnership with No Margin, No Mission, a national consulting firm dedicated to helping nonprofit organizations increase their earned income and entrepreneurial capacity. With the guidance of No Margin, No Mission, we are in the process of developing a Brain Injury Navigation Service for individuals with brain injury (including concussions) and their families who need a more intense level of support beyond the scope of the BIACT Helpline and who are not eligible for state-funded services. This earned income venture will be critical for BIACT as we look to new ways to support our mission in a time when state funding for BIACT programs continues to decline.

We are also encouraged that for the first time in many years, a universal motorcycle helmet bill has a real chance at passing the state legislature. BIACT is part of a coalition of safety advocates and motorcycle riders who are advocating for this bill. It has the support of the Governor, however, with strong lobbying from opponents, it still faces a difficult road ahead.

### Brain Injury Alliance of Idaho



BIAID (Idaho) is looking forward to a face-to-face meeting soon in the spring. We are planning our future fund raising and outreach activities for the coming year.

Three Board members just traveled to the Northwest Brain Injury Conference held annually in Portland, OR. One member participated with a major presentation and another attendee from Idaho presented as well.

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## Brain Injury Alliance of Iowa



The Brain Injury Alliance of Iowa was featured in a CBS2/FOX 28 news segment on concussion recently. To see the clip, [click here](#). Excerpts from the feature follow below.

“Brain injury is the last thing on your mind until it is the only thing on your mind,” said Geoffrey Lauer, CEO of the Brain Injury Alliance.

In 2018, the Iowa legislature updated state concussion law to ensure high school officials and health care providers take more steps before a concussed student can go back on the field. “It’s a multi-step process, 5 or 6 steps where you start with some easier exercise, progressed to more sport specific drills before you see contact and before you go all the way back to full practice and full play,” said Dr. Andy Peterson, Associate Professor of Pediatrics with University of Iowa Sports Medicine. “Most people were already doing that kind of stuff. This law really puts those things more officially into the law.”

The law also requires ‘return to learn’ protocols for schools, which is how and if a student can go back to learning after their concussion. “Teachers have been overwhelmed by many responsibilities, and sadly, this is another one, where sadly the health of students is now impacted by the quality of their experience during the day,” said Lauer.

Lauer said this area of the law still needs work, such as providing funding to educate teachers on how to best accommodate for their athletes recovering from a concussion and returning to the classroom. “Without the need to frame it as a disability, because it’s not a

disability,” he said. “It’s, hopefully a short-term health condition.”

Helping young athletes recover, however, is not just about resources at school. “We always felt like there was a gap for parents who thought they couldn’t afford to take their son or daughter to a doctor for a diagnosis,” said Alan Beste, Executive Director of the Iowa High School Athletic Association. The IHSAA said they have paid 59 claims for high school athletes since starting their free concussion insurance program in August, its offered to all players in men and women’s high school sports in the state. “The interesting thing to me is, while the majority of those were in football, there were also claims paid in wrestling and there were claims paid in swimming, so it’s not just a single sport type of insurance,” said Beste.

Beste recognizes some holes in the program like families and coaches may not know free insurance is available, but they hope this will change over time. Medical experts said identifying and treating high school concussions before it’s too late is still improving overall.

“Now all 50 states have these types of concussion laws, and it’s about doubled or tripled the number of people that are seeking medical care for sport related concussions,” said Peterson. “We think that this has created increased awareness and more people are actually seeking care for their concussions than before.”

The Brain Injury Alliance of Iowa will be presenting a proposal at the state capitol, asking for state funding that will go towards educating teachers about how to assess a student’s concussion related injury.

## Minnesota Brain Injury Alliance



This spring, the Minnesota Brain Injury Alliance launched the #BeTheAwareness campaign, where we encourage members of the brain injury community to raise awareness in their immediate circles by sharing their personal stories of brain injury with trusted listeners. #BeTheAwareness launched in March and is expected to run throughout the year with participants sharing their success stories online.

Unmasking Brain Injury in Minnesota has continued its incredible streak by partnering with UCare to arrange mask displays and mask-making sessions at the IDS Center’s Crystal Court in Minneapolis. Upcoming events include mask-making sessions at Crayola Experience in the Mall of America in Bloomington and mask-making sessions and a display at the Center Court in Southdale Center in Edina, Minnesota.

The 34th Annual Conference for Professionals in Brain Injury is on April 25 and 26. We’ve got some fantastic presentations in store this year, covering such diverse topics as neuropsychological testing, exercise after brain injury, compassion fatigue, pool therapy and many others. We also have as our Thursday keynote Dr. Shannon Juengst of University of Texas Southwestern Medical Center presenting on patient-centered measures for self-reported outcomes; and on Friday, Dr. Dean Beebe of Cincinnati Children’s Hospital Medical Center will be presenting his keynote on sleep disruption after pediatric brain injury. Our plenary sessions will feature Holly Kostrzewski giving Thursday’s talk on living with the effects of brain injury while Nancy Carlson will wrap up the conference on Friday by discussing her journey as caregiver to her husband who had frontotemporal dementia.

Finally, the Minnesota Brain Injury Alliance

continues its free offerings to families with the June 1 Consumer and Family Conference. This summer's conference will focus on building and strengthening relationships following brain injury, particularly when one of the members becomes a caregiver. Leslie J Meyer, Licensed Psychologist at Courage Kenny Rehabilitation Institute in Golden Valley will present "Toolbox for Success" which covers sources of stress within relationships, the consequences of stress, and different aspects of communication. Chad Martin, a software engineer at Medtronic, will present "Keeping Your Relationship Strong." Nearly six years ago, Chad's wife, Pam, suffered a major stroke. Chad has developed several lessons on maintaining a strong partnership throughout the recovery process that involves mutual respect and expectations even in a caregiving capacity.

For more information about either of these conferences, or any of the Minnesota Brain Injury Alliance's services, visit [www.braininjurymn.org](http://www.braininjurymn.org) or call 612-378-2742 800-669-6442.

### Brain Injury Alliance of Nebraska



In 2018 Brain Injury Alliance of Nebraska (BIA-NE) areas of focus included:

#### Education

BIA-NE offered 43 brain injury trainings across the state in which BIA-NE had over 2040 community-based professionals attend. Of these professionals attending the trainings, 977 of them came specifically to learn about the intersection of brain injury and domestic violence and the use of the modified HELP brain injury screening tool. Other areas of focus included juvenile justice, aging, corrections, veterans, and behavioral health.

BIA-NE hosts an annual brain injury conference in Kearney which brought

together over 220 professionals and individuals with brain injury and their families to learn about brain injury and industry standards.

The BIA-NE leads the Nebraska Concussion Coalition which promotes statewide concussion recognition and management. In 2018, BIA-NE and partners surveyed over 2,600 school administrators, teachers, and allied professionals to evaluate schools' implementation of concussion policies, with a focus on the topic of students returning to the classroom after sustaining a concussion ("return-to-learn"). Survey results will help direct training in 2019.

#### Advocacy

Legislative wins included the retention of the motorcycle helmet law in Nebraska. BIA-NE held a brain injury advocacy day, participated in Disability Pride Day, and interviewed the 2018 legislative candidates across the state.

BIA-NE created an Engagement Committee in Omaha and North Platte. Members have the skills and interests to build grassroots advocacy and locate/increase supports for individuals/families in their community living with brain injury.

#### Support

Volunteer facilitated Brain Injury Support Groups meet regularly in 16 locations throughout Nebraska. Resource Facilitation Specialists, who, through strategic partnerships provide individualized information, resources, and referral services to individuals and their families coping with brain injury. From July 2016 to December 2018 BIA-NE worked with over 450 unique clients.

### Brain Injury Alliance of New Jersey



BIANJ held their annual Walk for Brain Injury Awareness

on Saturday, October 6, 2018. The Walk is now being held simultaneously at four locations throughout the state. For the first time, BIANJ incorporated a 5k run into this event at two locations and hopes to grow the number of 5k participants moving forward. It was a fun day of raising awareness for all!

BIANJ celebrated the holiday season by hosting another successful Adopt-A-Family holiday drive in 2018. Corporations, service groups, schools and individuals delighted in shopping for our families to make their holiday season extra special. This year, BIANJ held its first ever Family Holiday Party. What started as an idea to offer an opportunity to families to socialize and retrieve their donated gifts, turned into an inspirational and fun-filled event. A special thank you to Board Member, Richard Anderson, for playing Santa and bringing smiles to all the families and CHIC members. As one mom told us, her son "hasn't smiled in a year and without BIANJ, there would have been no Christmas." Thank you to our generous donors for making the holiday season special for these families.

BIANJ is hosting its 13th Annual Gala, Shining the Light on Caregivers, on March 27, 2019. The event is honoring Past BIANJ Board Chair and Caregivers, Wallace and Lori Kyle, Executive Director of Mt. Bethel Village, Carolann Garafola, and Founders of the Sean Reilly TBI Fund and Caregivers, Bill and Susan Reilly.

BIANJ's annual Health and Human Services Trainings will take place in two locations in New Jersey this spring. The topic, Domestic Violence and Brain Injury, will bring together experts to provide a better understanding of the relationship between brain injury and domestic violence and highlight available resources.

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The 37th Annual Seminar for Professionals, Moving Forward in Brain Injury: Evidence in Action will be held on May 14, 2019. The keynote speaker, Daniel P. Perl, MD will present The Long-Term Effects of Military TBI: Is it Like Playing NFL Football, or is it Something Else? Dr. Perl is the Director of the Center for Neuroscience and Regenerative Medicine and Neuropathology Care at the Uniformed Services University of the Health Sciences. A sampling of the workshops at the conference includes: Executive Function in Pediatric Traumatic Brain Injury; Interdisciplinary Rehabilitation; Craniosacral Therapy; Sex and Intimacy; and Neurotoxicity.

BIANJ has partnered with the Rutgers University Youth Sports Research Council to create an online concussion course for youth sports coaches. The course will be available for coaches in the Spring of 2019. BIANJ is partnering with Princeton University and Capital Health – Capital Institute for Neurosciences on March 30 to present a seminar on the changing concept of concussion and evolving research that suggests potentially more serious and long-lasting consequences surrounding this injury.

BIANJ continues to present on a variety of brain injury prevention and education topics across the state to diverse audiences including school children, senior citizens, and families that have recently been touched by brain injury. In the last quarter of 2018 alone, BIANJ staff presented and/or exhibited at 98 events to 5,897 people on topics such as Adjustment to Brain Injury, Concussion Awareness, and Motorcycle and Pedestrian Safety.

BIANJ instituted a “Live Chat” as part of its Information and Resources Helpline, to increase accessibility and address changes in technology and resource facilitation.

## Brain Injury Alliance of Washington



The Brain Injury Alliance of Washington (BIAWA) held our 12th Annual Brain Injury Gala, Dinner, & Auction on November 3, 2018 in Seattle, WA. This year’s Gala focused on the theme of Igniting Hope. Honorary Chairs at the Gala was the Lystedt Family: Victor, Mercedes, and Zackery. Zackery sustained a life-changing Brain Injury when he was injured playing High School football in 2006. Thanks to this family’s perseverance, a law was mandated in the state of Washington on Return-To-Play protocol and every state has since followed suit.

Following the theme of Igniting Hope, Seth Barronian and his family were showcased in an inspiring video of their journey with Brain Injury. You can watch it [here](#).

We will be hosting our 11th Annual Brain Injury Art Show this year at the Seattle Art Museum. The seven-week exhibit during the months of June and July will give survivors a special opportunity to share their artwork and their story of recovery at this highly renowned Museum in Downtown Seattle.

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### OUR MISSION

The mission of the United States Brain Injury Alliance is to engage the community in preventing brain injuries and improving lives. We will accomplish this through awareness, prevention, advocacy, support, research, and community engagement.

[www.usbia.org](http://www.usbia.org)